

Medicaid: The Key to good health for child with rare heart/lung condition

My oldest daughter, Carissa, was born with both Down syndrome and a rare heart/lung condition called Pulmonary Hypertension, (PH). When she was first diagnosed with PH, we were told that nothing could be done, and that her life span would be significantly shortened.



Carissa is now 14 years old, in great health and will be starting High School in our local public school in the fall. She is very active; she likes playing basketball, walking, and swimming and loves acting in school and community plays. A team of nurses, doctors, specialists, and other health care professionals spanning three states have all contributed to her good health.

Medicaid has allowed us access to this network of healthcare providers. No private health insurance would cover the range of specialists and provide the consistency of care and access to the necessary specialists to treat the Pulmonary Hypertension.

Numerous health challenges can be common for children with Down syndrome. Carissa had heart surgery as a baby and has gone on to develop asthma, reflux, hair loss from alopecia, frequent ear infections with hearing loss in both ears requiring hearing aids, special bi-focal glasses, and sleep apnea requiring a bi-pap machine with night nursing to monitor her breathing. Not so common to Down syndrome, Carissa also has the serious chronic life threatening condition called Pulmonary Hypertension.

Pulmonary hypertension is abnormally high blood pressure in the arteries of the lungs. It makes the right side of the heart need to work harder than normal. There is no known cure. The goal of treatment is to control symptoms. The main symptom that Carissa experiences is extreme tiredness especially with any excursion. Imagine how tough that is for her to manage and for our family to plan around! For Carissa a common cold is never just a cold. Any upper respiratory infection, like she constantly has with her ears, or typical childhood illness can quickly become a very serious health crisis with PH. Although the long-term outlook has been poor, new drug therapies are producing better results. Early on I learned from other people with PH that treatment at a center that specializes in treating only PH was crucial to her survival.

The key to Carissa doing so well has been the treatment she has received from the Pulmonary Hypertension Center located at New York- Presbyterian Morgan Stanley Children's Hospital. This is the only condition that the pediatric cardiologists treat and they have been at the forefront of drug trials for PH. **Medicaid** has allowed us to get this treatment and participate in drug trials when necessary. With traditional private health insurance our team of specialists would never all be in one network and our family would be bankrupt trying to pay for this care.

Carissa's health has a profound effect on the well being of the rest of the family. When Carissa is doing well we all are doing much better! With **Medicaid** our family is assured that she will receive the health care that she requires to keep her functioning at her best.